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Patient reported "ever had" and "current" long term physical symptoms following prostate cancer treatments.

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Keywords: Prostate cancer, patient reported physical outcomes.

Conflicts of Interest

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Abstract

Objective: To document prostate cancer patient reported 'ever experienced' and 'current' prevalence of disease specific physical symptoms stratified by primary treatment received.

Patients: 3,348 prostate cancer survivors 2-15 years post diagnosis.

Methods: Cross-sectional, postal survey of 6,559 survivors diagnosed 2-15 years ago with primary, invasive PCa (ICD10-C61) identified via national, population based cancer registries in Northern Ireland and Republic of Ireland. Questions included symptoms at diagnosis, primary treatments and physical symptoms (impotence/urinary incontinence/bowel problems/breast changes/loss of libido/hot flashes/fatigue) experienced 'ever' and at questionnaire completion ("current"). Symptom proportions were weighted by age, country and time since diagnosis. Bonferroni corrections were applied for multiple comparisons.

Results: Adjusted response rate 54%; 75% reported at least one 'current' physical symptom ('ever':90%), with 29% reporting at least three. Prevalence varied by treatment; overall 57% reported current impotence; this was highest following radical prostatectomy (RP)76% followed by external beam radiotherapy with concurrent hormone therapy (HT); 64%.

Urinary incontinence (overall 'current' 16%) was highest following RP ('current'28%, 'ever'70%). While 42% of brachytherapy patients reported no 'current' symptoms; 43% reported 'current' impotence and 8% 'current' incontinence. 'Current' hot flashes (41%), breast changes (18%) and fatigue (28%) were reported more often by patients on HT.

Conclusion: Symptoms following prostate cancer are common, often multiple, persist long-term and vary by treatment. They represent a significant health burden. An estimated 1.6%

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of men over 45 is a prostate cancer survivor currently experiencing an adverse physical symptom. Recognition and treatment of physical symptoms should be prioritised in patient follow-up. This information should facilitate men and clinicians when deciding about treatment as differences in survival between radical treatments is minimal.

Keys words: Prostate Cancer, Population, Patient Reported Outcomes

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Introduction

Prostate cancer (PCa), the most common cancer in males in developed countries, has an estimated 900,000 new cases annually, 325,000 of which occur in Europe.[1] Driven by ageing populations, widespread PSA testing and improved survival, PCa prevalence is predicted to rise in the UK from an estimated 255,000 in 2010 to 831,000 cases by 2040.[2] In Ireland, PCa currently accounts for 34% of male cancer survivors (excluding non-melanoma skin cancers) in Northern Ireland (NI) and approximately 40% in the Republic of Ireland (RoI).[3-5]

All PCa treatments carry the potential for adverse effects including impotence, incontinence, bowel problems, hot flashes and fatigue.[6] Since studies have not conclusively shown survival benefits of one treatment over another for localised PCa robust population based estimates of prevalence and duration of symptoms post-treatment are valuable for informing treatment decision-making. [7-12]

The majority of studies on side effects to date are from clinical trials which do not compare all treatment modalities, exclude older men and do not extend beyond 10 years.[13-16] Our aim was to investigate the prevalence of physical symptoms that were 'ever' experienced and are 'currently' experienced at a population level, assess burden and inform policy to support medium to long term PCa survivors.

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Patients and Methods

The study took place on the island of Ireland. Northern Ireland (NI) has a predominantly publically-funded health care system, whereas the Republic of Ireland (RoI) has a mixture of public and private health care. The same approach was used in both settings to identify and recruit participants. All men diagnosed with invasive PCa (ICD10 C61) between 1/1/1995 and 31/03/2010 and alive at 31st March 2011 were identified through population based cancer registries (NI=5,519; RoI=17,304). A random sample of survivors was screened for eligibility by healthcare providers (n=12,322, 52% of total sampling frame). Eligible survivors were: aware of their diagnosis; English speaking; resident in either NI or RoI; and well enough to complete a questionnaire (in particular had no cognitive impairment).

In NI, eligibility was checked by research nurses, or the patient's general practitioner (GP). In RoI, the patient's GP confirmed eligibility. In both areas, survivors whose eligibility was not confirmed e.g. GP non-response, were excluded. Following this process, 6,559 (53% of the random sample) were deemed eligible for invitation to complete a postal questionnaire (Figure I).

A questionnaire including the EORTC QLQ C30, PR25, EQ5D-5L, DASS 21 and Decisional Regret Scale was developed following literature review with clinician and patient input.[17-21] Questions included socio-demographic characteristics and pre-diagnosis symptoms (urinary problems [increased frequency, pain urinating, blood in urine], bowel problems [diarrhoea, constipation], and/or sexual dysfunction - impotence and loss of libido). Information on the latter two were requested 'ever' after treatment, 'currently' at

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questionnaire completion and pre-diagnosis. A list of PCa treatment modalities was included and survivors were asked to indicate all treatments received, with dates. Specific questions were asked about seven potential disease or treatment related symptoms at two time points; 'ever' (i.e. anytime since treatment) and 'current' (i.e. at time of questionnaire completion). The symptoms considered were urinary incontinence, impotence, loss of libido, bowel problems, breast changes, hot flashes and fatigue.

The draft questionnaire was pre-tested among 32 PCa survivors for acceptability, ease of understanding and face validity and modified accordingly. Questionnaires were dispatched between April-September 2012. Each man received a cover letter, information sheet, consent form and freepost return envelope with their questionnaire. Non-responders received up to two written reminders. Date of diagnosis, clinical stage and Gleason grade (GG) at diagnosis were extracted from cancer registry databases. GG is collected and categorised as low (<5), medium (6-7) and high (>8) and not as raw data by the registry. Additional information was sourced for staging/GG for NI responders as these data were incomplete in routine data for earlier years.

For survivors who answered some treatment or physical symptom questions, but omitted others from that section, a "no" response was assumed. Non-response to all of 5 treatment questions (3%, n=93), or all 14 symptom questions (3%, N=102), were coded as "missing" but retained in analyses.

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To investigate whether symptoms varied by time since diagnosis, respondents were categorised into three groups: 2-4.9 years, 5-9.9 years and ≥10 years post-diagnosis. To study symptoms by treatment, a variable was created based on a mutually exclusive hierarchy of treatments: each man was categorised once based on primary treatment(s) received: **RP** = Radical Prostatectomy at any time following diagnosis (with or without other treatments); **EBRT with HT =** External Beam Radiotherapy with concurrent hormone therapy within six months; **EBRT without HT =** External Beam Radiotherapy without concurrent HT; **BT=** Brachytherapy, excluding survivors with previous EBRT or RP; **HT =** Hormone Therapy alone without radical prostatectomy, external beam radiotherapy or brachytherapy; **CT =** Chemotherapy alone**; MON =** Monitoring including active surveillance or watchful waiting.

Survivors were also categorised as: 1) currently on HT 2) previously received HT and 3) never had HT. Pre and post treatment experience was compared for loss of libido and impotence.

Comparisons of symptom proportions across treatment groups were tested for significance at the 5% level using two-sided z-tests based upon weighted counts rounded to the nearest whole number, with differences in overall distributions tested using chi-square tests. Bonferroni corrections were applied to account for multiple comparisons. The Clopper Pearson interval method was used to generate exact 95% binomial confidence intervals for weighted proportion estimates. [22]

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To extrapolate results to the entire PCa survivor population, weighted proportions of symptoms were computed. Respondents' characteristics were compared with those of all PCa survivors in Ireland (i.e. the total sampling frame) and the proportions with each symptom was adjusted with weights based on country, age at diagnosis and time since diagnosis.

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Results

In total 3,348 men responded, representing a 54% response rate after adjusting for eligibility following questionnaire dispatch. Respondents' average age was 64·9 years (standard deviation 7·6). Compared to all PCa survivors, respondents were younger at diagnosis (χ^2=49·6; p<0·001), diagnosed more recently (χ^2=164·8; p<0·001), had their cancer staged (χ^2= 673·0; p<0·001) and graded (χ^2=653·1; p<0·001) (Table 1). Two thirds of respondents (64%) had presented with early disease (stage I/II), while 65% had an intermediate Gleason grade (5-7) at diagnosis. Almost half, 48%, were surveyed 2-4·9 years post-diagnosis, 32% were 5-9·9 years and 20% ≥10 years. Those in the ≥10 year group were younger at diagnosis, less often had stage I/II disease and more often had low-grade disease compared with those diagnosed more recently (all comparisons p<0·001). They also more often reported RP treatment and less often BT or EBRT with HT (all comparisons p<0·001). At diagnosis over half (51.2%) of men reported urinary frequency, 18.8% impotence and 14.7% loss of libido. There were no significant variations in pre-treatment symptoms reported between groups diagnosed at different time periods (Table 2). The responder's treatment categories were compared with data from both cancer registries taken in 2001. The levels of chemotherapy (2% responders, 1.4% registry [p=0.11]), hormone therapy (45% responders, 44% registry[p=0.46]) and radical prostatectomy (27% responders, 38% registry [<0.01]) were within the range of the overall prostate cancer population. The levels of radiotherapy were higher among responders at 58%, 24% registry [<0.01], in keeping with but not completely explained by increased use over time (RoI average 41% for 2007-2011).

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'Ever had' physical symptoms: (weighted proportions)

Overall, 90% of respondents, reported 'ever' experiencing at least one of the seven possible physical symptoms investigated post-treatment, 61% reported at least three, 20% four, one in eight (12.5%) reported five, 6% reported 6 and 2% reported all seven symptoms. Most common were impotence (68%), loss of libido (58%) and fatigue (55%). There was significant variation in "ever" had symptoms by time since diagnosis. Loss of libido was more common in men 2-4·9 years since diagnosis compared to those ≥10 years post-diagnosis (60% vs 54%, respectively, p=0·010). Bowel problems (26% of all respondents) and fatigue (55% of all respondents) were less common among those ≥10 years post-diagnosis compared to other diagnosis periods, bowel (2-4·9 years, p<0·001; 5-9·9 years, p=0·004), fatigue (2-4·9 years, p<0·001; 5-9·9 years, p=0·007) (Table 3).

'Current' physical symptoms: (weighted proportions)

Three-quarters reported at least one 'current' symptom with 29% reporting three or more, and 4% at least five. 65% reported currently having impotence, urinary incontinence and/or bowel problems, and 57% reported at least one of the following; loss of libido, breast changes, fatigue or hot flashes (Figures 2a and 2b). There was no significant difference in proportions of 'current' symptoms between groups diagnosed during different periods. For each symptom, 'current' proportions were lower than 'ever'. The biggest differences were for fatigue (ever, 55%; current, 22%), hot flashes (39%, 6%) and urinary incontinence (37%, 16%), and the smallest for impotence (68% vs 57%). One quarter of survivors (25%) reported no 'current' physical symptoms (Table 3).

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Pre-and Post-treatment comparisons:

Pre- and post-treatment comparisons were possible for impotence and loss of libido. Prior to diagnosis, 19% reported impotence, increasing with age at diagnosis from 16% of those <60 years, to 21% of men aged ≥70 years. Impotence as a new current symptom post-treatment was reported by 43%, while 5% reported impotence pre-treatment, but not currently. This varied by primary treatment being highest following prostatectomy. Loss of libido was reported pre-diagnosis by 15% of survivors; 5% reported this pre-treatment but not currently; and 46% report 'current' loss of libido but not pre-treatment (Figure 3).

Variations in 'current' physical symptoms by primary treatment:

Among men treated with RP proportions of 'current' impotence (76%) and urinary incontinence (28%) were higher than the average for all respondents (weighted proportions; p<0·001) while bowel problems (9%), hot flashes (7%) and breast changes (3%) post-RP were lower than average (p<0·001 for all three comparisons).

Men treated with EBRT with concurrent HT reported the highest proportions of current bowel problems (20%) compared to HT (9%), RP (9%), BT (7%) or MON (2%). Survivors treated by EBRT with concurrent HT, compared to those who had EBRT without concurrent HT, reported more 'current' loss of libido (58% vs 43%, p<0.001), impotence (64% vs 50%, p<0·001), breast changes (20% vs 9%, p<0·001), hot flashes (28% vs 15%, p<0·001) and fatigue (32% vs 23%, p<0·001).

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Those treated with BT reported lower than average proportions of 'current' impotence (43%), loss of libido (26%), hot flashes (2%), and breast changes (2%); 42% of this group reported no 'current' problems.

Men treated with HT alone reported high proportions of 'current' loss of libido (52%), impotence (51%), hot flashes (41%) and fatigue (28%); while 20% reported no 'current' physical symptoms.

64% of men on monitoring reported no 'current' physical symptoms, higher than other groups ($p<0{\cdot}001$). One in five men on monitoring reported loss of libido or impotence (21%), (only slightly higher than pre-treatment average levels - 19%), loss of libido (22%), other symptoms were less common in the monitoring group (urinary incontinence (7%), hot flashes (4%), fatigue (4%), bowel problems (2%) and breast changes (2%) (Table 3).

Variation in 'current' symptoms by hormone therapy:

Overall 45% reported receiving HT at some point post-diagnosis. Current use of HT (19%) compared to past use (26%), and never use (55%) was associated with more hot flashes, (54% current vs 15% past vs 4% never), loss of libido (62% current vs 50% past vs 38% never), breast changes (23% current vs 14% past vs 2% never) and fatigue (38% current vs 23% past vs 16% never) (all comparisons significant $p < 0{\cdot}001$) (Figure 4).

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Discussion

This large population-based study adds to the literature in this area by examining seven disease specific physical symptoms of men of all ages with prostate cancer up to 15 year post-diagnosis. All treatment modalities were included in two countries with high standards of services and patient care. This has allowed us to estimate the population burden of physical symptoms as reported by men, their patterns following different treatments and their "persistence". In light of the uncertainties around optimal treatment from a clinical outcome perspective this type of information on patients reported outcomes is potentially extremely valuable for informing treatment decision-making.

The burden of symptoms is high with many survivors reporting multiple symptoms. Nine out of ten men reported at least one of the seven possible symptoms at some point post-diagnosis, and three quarters reported at least one as 'current'. However, about one in ten survivors reported no symptoms at any time and 25% were currently symptom free.

Over half (57%) reported 'current' impotence, almost half (46%) loss of libido and one in six 'current' urinary incontinence, with fatigue a common complaint. Urinary incontinence and impotence were more common post-RP compared to other treatments and bowel problems most common post-EBRT. The pattern of these symptoms was as documented in smaller studies reporting on specific treatments. [9, 12, 23-25] However, this study which looks at the total population of survivors allows as estimate of total burden.

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With regard to impotence, men reported current levels of 57% and ever at 68%. This work extends that of Korfage *et al,* who found that 52 months following treatment, 88% of men treated with RP and 64% of those who had EBRT with concurrent HT reported erectile dysfunction.[26] We found similar high levels by examining men up to 15 years post diagnosis supporting Korfage's assertions that erectile dysfunction is likely to be permanent if present 12 months or more post-treatment.

The effect of HT in improving survival has been documented, but at a cost of symptoms such as loss of libido, fatigue, hot flashes and breast changes.[12,27,28] Consistent with this, and reported for a large cohort, those currently on HT were approximately 10-times more likely to report breast changes and hot flashes than those who never had HT. High levels of fatigue for those on HT is similar to clinical studies.[29,30]

An important part of our analysis related to the prevalence of symptoms at different times since diagnosis. The lower proportion of bowel problems reported by survivors diagnosed ≥10 years ago likely reflects lower rates of EBRT in that cohort (confirmed by cancer registry data) as well as improvements in technologies. The fact that the proportions who reported 'ever' and 'current' symptoms were similar in each survival period, indicates a need for ongoing support after PCa treatment.

Implications

UK guidelines recommend that survivors and their partners are given opportunities to discuss psychosexual problems and that counselling on sexual problems and urinary

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incontinence is available as long as needed.[7] Our results suggest there is likely to be a large need with three quarters of men reporting at least one physical symptom, almost 60% current impotence and one in six reporting current incontinence.

Based on this work, of the 22,823 PCa survivors resident in Ireland at the time of the study, we estimate that 17,100±300 had at least one 'current' physical symptom; including impotence (13,100±400) loss of libido (10,400±400), fatigue (5,000±300) and urinary incontinence (3,600±300). Based upon the 2011 Censuses in both countries, we estimate that 1.6% of the male population aged 45 and over is a PCa survivor with a 'current' physical symptom, 1.2% with impotence and 1% loss of libido. This represents a significant number of men who require ongoing care. The information in this study could also be used to help inform decisions about investigation and treatment of PCa and survivors' expectation of symptoms.[23,31] Recognition and treatment of physical symptoms should be prioritised in patient follow-up.

Strengths

Unlike other similar patient-reported outcome studies in PCa, this study included men of all ages, treated with all available modalities.[31-33] It covered a longer period since diagnosis.[9,23] High-quality cancer registries provided the basis for sampling and this allowed population representativeness to be assessed and proportions weighted so that estimates are of the symptoms burden in the entire survivor population. Self-reported treatment was compared with treatment information from each registry; congruence for RP was 86% in NI and 70% in RoI, and for EBRT was 96% in NI and 75% in RoI. Weighting allowed us to address some demographic aspects of non-response.

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Limitations

As with many questionnaire studies, older persons were less likely to respond but weighted proportions allowed adjustment for this.[6] Also, as a cross-sectional study, comparisons between groups diagnosed at different time periods have limitations due to changing treatment, investigation patterns and different patient profiles. We recognise that accuracy of recall as a potential limitation, for example, the 4% of survivors in the monitoring group reporting 'current' hot flashes may represent contamination of treatment recall with survivors not recognizing that they are having HT.

While we have documented symptoms reported by PCa survivors, we recognise that not all can be attributed to PCa treatments. Erectile dysfunction increases with age.[34,35] We have reported pre and post treatment levels of impotence and these increased with age from 16% of men under 60, to 18.7% in men aged 60-69 and 20.4% in men aged 70+. The same men responded to post treatment levels of impotence at 66.4% < 60 years, 61.5% 60-69 years, 45.9% aged 70+. These figures reflect the higher rates of radical prostatectomy in younger men and monitoring in older men. Urinary incontinence in general male populations, without PCa, has been estimated to be between 3 and 11%.[36-37] Urinary incontinence among the Irish population has been reported at 4.5% for men over 50 years, ranging from 2-4% for men aged 50-64, 4-7% for ages 65-74 and 6-11% for those aged over 75 years [38] lower than the 16% ongoing incontinence reported post treatment. Some of the reported physical symptoms may however be due to co-morbidities, or other treatments e.g. breast changes due to commonly used medications.[36,37] Future studies should collect normative data for the male population to better determine treatment effects.

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In conclusion, physical symptoms following PCa are common, often multiple and persist years after diagnosis representing a large health burden.

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Table 1 - **Characteristics of prostate cancer populations: all survivors, random sample, eligible survivors, responders and non-responders**

		All survivors	Random sample	Eligible for study	Responders	Non-responders
Total		N=22,823	N=12,322	N=6,559	N=3,348	N=3,211
		Number and % of total survivors in each column				
Age at diagnosis	0-59	5,046 (22·1%)	2,039 (16·5%)	1,329 (20·3%)	799 (23·9%)	530 (16·5%)
	60-69	10,212 (44·7%)	4,891 (39·7%)	2,939 (44·8%)	1,631 (48·7%)	1,308 (40·7%)
	70+	7,565 (33·1%)	5,392 (43·8%)	2,291 (34·9%)	918 (27·4%)	1,373 (42·8%)
Time since diagnosis	2-5 yrs	9,569 (41·9%)	5,340 (43·3%)	3,101 (47·3%)	1,614 (48·2%)	1,487 (46·3%)
	5-9·9 yrs	9,776 (42·8%)	4,324 (35·1%)	2,114 (32·2%)	1,075 (32·1%)	1,039 (32·4%)
	≥10 yrs	3,478 (15·2%)	2,658 (21·6%)	1,344 (20·5%)	659 (19·7%)	685 (21·3%)
TNM stage*	I/II	12,761 (55·9%)	5,792 (47·0%)	3,817 (58·2%)	2,126 (63·5%)	1,691 (52·7%)
	III	2,122 (9·3%)	1,130 (9·2%)	947 (14·4%)	612 (18·3%)	335 (10·4%)
	IV	690 (3·0%)	445 (3·6%)	267 (4·1%)	141 (4·2%)	126 (3·9%)
	Unknown	7,250 (31·8%)	4,955 (40·2%)	1,528 (23·3%)	469 (14·0%)	1,059 (33·0%)
Gleason grade*	2-4	1,578 (6·9%)	923 (7·5%)	472 (7·2%)	212 (6·3%)	260 (8·1%)
	5-7	11,766 (51·6%)	4,996 (40·5%)	3,609 (55·0%)	2,186 (65·3%)	1,423 (44·3%)
	8-10	2,865 (12·6%)	1,594 (12·9%)	1,060 (16·2%)	625 (18·7%)	435 (13·5%)
	Unknown	6,614 (29·0%)	4,809 (39·0%)	1,418 (21·6%)	325 (9·7%)	1,093 (34·0%)

*Further information was sourced for TNM stage and Gleason grade for NI responders only. This is reflected in the lower percentage with stage unknown among responders compared to the other columns

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Table 2 - **Characteristics of responders by time since diagnosis**

		2-4·9 years post diagnosis (n=1,614)		5-9·9 years post diagnosis (n=1,075)		≥10 years post diagnosis (n=659)		All respondents (n=3,348)	
Age at diagnosis	0-59	340	(21·1%)	255	(23·7%)	204	(31·0%)	799	(23·9%)
	60-69	750	(46·5%)	534	(49·7%)	347	(52·7%)	1631	(48·7%)
	70 and over	524	(32·5%)	286	(26·6%)	108	(16·4%)	918	(27·4%)
Age at questionnaire completion	0-59	186	(11·5%)	45	(4·2%)	12	(1·8%)	243	(7·3%)
	60-69	637	(39·5%)	346	(32·2%)	102	(15·5%)	1085	(32·4%)
	70 and over	791	(49·0%)	684	(63·6%)	545	(82·7%)	2020	(60·3%)
Stage	Stage I/II	1120	(69·4%)	670	(62·3%)	336	(51·0%)	2126	(63·5%)
	Stage III	323	(20·0%)	183	(17·0%)	106	(16·1%)	612	(18·3%)
	Stage IV	81	(5·0%)	36	(3·3%)	24	(3·6%)	141	(4·2%)
	Unknown	90	(5·6%)	186	(17·3%)	193	(29·3%)	469	(14·0%)
Gleason grade	Low (2 to 4)	66	(4·1%)	51	(4·7%)	95	(14·4%)	212	(6·3%)
	Intermediate (5 to 7)	1035	(64·1%)	769	(71·5%)	382	(58·0%)	2186	(65·3%)
	High (8 to 10)	356	(22·1%)	170	(15·8%)	99	(15·0%)	625	(18·7%)
	Unknown	157	(9·7%)	85	(7·9%)	83	(12·6%)	325	(9·7%)
Symptom at diagnosis	Frequency of urine	821	(50·9%)	547	(50·9%)	346	(52·5%)	1714	(51·2%)
	Pain while urinating	103	(6·4%)	88	(8·2%)	65	(9·9%)	256	(7·6%)
	Blood in urine	94	(5·8%)	72	(6·7%)	53	(8·0%)	219	(6·5%)
	Impotence	356	(22·1%)	184	(17·1%)	91	(13·8%)	631	(18·8%)
	Loss of libido	247	(15·3%)	163	(15·2%)	83	(12·6%)	493	(14·7%)
	Back pain	261	(16·2%)	161	(15·0%)	84	(12·7%)	506	(15·1%)
Primary Treatment	RP	374	(23·2%)	305	(28·4%)	255	(38·7%)	934	(27·9%)
	EBRT with concurrent HT	383	(23·7%)	179	(16·7%)	68	(10·3%)	630	(18·8%)

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	EBRT without concurrent HT	484	(30·0%)	391	(36·4%)	213	(32·3%)	1088	(32·5%)
	BT	87	(5·4%)	33	(3·1%)	4	(0·6%)	124	(3·7%)
	HT	147	(9·1%)	91	(8·5%)	72	(10·9%)	310	(9·3%)
	MON	102	(6·3%)	44	(4·1%)	18	(2·7%)	164	(4·9%)
	Missing	34	(2·1%)	31	(2·9%)	28	(4·2%)	93	(2·8%)

Note: Results not weighted for survey non-response bias. Chemotherapy omitted due to less than 5 respondents. Respondents may have more than one symptom.

RP: Radical prostatectomy, EBRT: External beam radiotherapy, HT: Hormone therapy, BT: Brachytherapy, MON: Monitoring

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Table 3 - Symptoms (Current and Ever) reported by PCa survivors, by primary treatment modality (weighted for country, age at diagnosis and time since diagnosis)

		RP	EBRT with concurrent HT	EBRT without concurrent HT	BT	HT	MON	Missing	All Respondents
		Proportion of men reporting symptom (95% CI)							
Average age at diagnosis(years)		60·5	66·4	67·1	61·7	73·5	67·9	69·0	64.9
Urinary incontinence	Ever had	70·3% (67·2%, 73·3%)	24·3% (20·8%, 28·0%)	27·3% (24·7%, 3·0%)	28·5% (20·7%, 37·3%)	21·3% (17·1%, 26·1%)	12·1% (7·6%, 18·1%)	23·5% (15·7%, 33·0%)	37% 35.4-38.7
	Current	27·8% (24·9%, 30·8%)	10·7% (8·3%, 13·5%)	11·8% (10·0%, 13·9%)	8·1% (4·0%, 14·4%)	14·5% (10·9%, 18·7%)	6·7% (3·4%, 11·6%)	12·7% (7·0%, 20·8%)	15.8% 14.6-17.1%
Loss of libido	Ever had	59·5% (56·2%, 62·7%)	74·4% (70·6%, 77·9%)	55·7% (52·8%, 58·7%)	41·5% (32·7%, 50·7%)	58·6% (53·1%, 63·9%)	26·1% (19·5%, 33·5%)	37·3% (27·9%, 47·4%)	57.8% 56.1%-59.5%
	Current	47·0% (43·7%, 50·3%)	58·0% (53·9%, 62·1%)	43·1% (40·2%, 46·1%)	26·0% (18·5%, 34·7%)	51·5% (46·0%, 56·9%)	21·8% (15·8%, 28·9%)	29·4% (20·8%, 39·3%)	45.5% 43.8-47.2%
Impotence	Ever had	87·6% (85·3%, 89·7%)	78·7% (75·1%, 81·9%)	59·6% (56·7%, 62·5%)	58·5% (49·3%, 67·3%)	59·2% (53·7%, 64·5%)	26·1% (19·5%, 33·5%)	42·2% (32·4%, 52·3%)	68.2% 66.6%-69.8%
	Current	75·5% (72·6%, 78·3%)	64·2% (60·2%, 68·1%)	50·2% (47·2%, 53·1%)	43·1% (34·2%, 52·3%)	50·9% (45·4%, 56·3%)	20·6% (14·7%, 27·6%)	29·4% (20·8%, 39·3%)	57.2% 55.5%-58.9%
Bowel problems	Ever had	16·6% (14·2%, 19·2%)	41·0% (36·9%, 45·1%)	33·1% (30·4%, 36·0%)	21·1% (14·3%, 29·4%)	14·2% (10·7%, 18·4%)	3·6% (1·3%, 7·7%)	9·8% (4·8%, 17·3%)	25.5% 24.1%-27.1%
	Current	9·2% (7·4%, 11·3%)	22·0% (18·7%, 25·6%)	19·2% (16·9%, 21·6%)	7·3% (3·4%, 13·4%)	9·2% (6·3%, 12·8%)	2·4% (0·7%, 6·1%)	4·9% (1·6%, 11·1%)	14.2% 13.1%-15.5%
Breast changes	Ever had	6·2% (4·7%, 8·0%)	39·6% (35·6%, 43·7%)	17·7% (15·5%, 20·0%)	1·6% (0·2%, 5·8%)	22·8% (18·4%, 27·6%)	2·4% (0·7%, 6·1%)	4·9% (1·6%, 11·1%)	17.2% 16.0%-18.6%
	Current	3·1% (2·1%, 4·5%)	20·0% (16·8%, 23·5%)	8·7% (7·1%, 10·4%)	1·6% (0·2%, 5·8%)	17·8% (13·8%, 22·3%)	1·8% (0·4%, 5·2%)	1·0% (0·0%, 5·3%)	9.3% 8.3%-10.3%
Hot flashes	Ever had	15·7% (13·4%, 18·3%)	79·9% (76·4%, 83·1%)	40·4% (37·5%, 43·3%)	11·4% (6·4%, 18·4%)	60·1% (54·6%, 65·3%)	6·1% (2·9%, 10·9%)	5·9% (2·2%, 12·4%)	38.7% 37.1-40.4%

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	Current	7·0% (5·4%, 8·8%)	27·7% (24·1%, 31·5%)	14·5% (12·5%, 16·7%)	2·4% (0·5%, 7·0%)	40·5% (35·3%, 46·0%)	3·6% (1·3%, 7·7%)	2·0% (0·2%, 6·9%)	16.0% 14.8-17.3%
Fatigue	Ever had	50·4% (47·1%, 53·7%)	74·0% (70·2%, 77·5%)	63·4% (60·5%, 66·2%)	44·7% (35·7%, 53·9%)	42·0% (36·7%, 47·5%)	8·5% (4·7%, 13·8%)	18·6% (11·6%, 27·6%)	54.9% 53.2-56.6%
	Current	18·1% (15·6%, 20·7%)	31·5% (27·7%, 35·4%)	22·8% (20·4%, 25·3%)	13·0% (7·6%, 20·3%)	28·4% (23·7%, 33·5%)	4·2% (1·7%, 8·5%)	4·9% (1·6%, 11·1%)	21.7% 20.3-23.2%
No symptom	Ever had	4·3% (3·1%, 5·9%)	1·2% (0·5%, 2·5%)	9·6% (8·0%, 11·5%)	17·1% (10·9%, 24·9%)	10·9% (7·8%, 14·8%)	58·2% (50·3%, 65·8%)	37·3% (27·9%, 47·4%)	10.4% 9.4-11.4
	Current	15·5% (13·2%, 18·0%)	16·5% (13·6%, 19·8%)	29·4% (26·8%, 32·2%)	41·5% (32·7%, 50·7%)	19·5% (15·4%, 24·2%)	63·6% (55·8%, 71·0%)	49·0% (39·0%, 59·1%)	25.2% 23.7-26.7%
Any symptom	Ever had	95·7% (94·1%, 96·9%)	98·8% (97·5%, 99·5%)	90·4% (88·5%,92·0%)	82·9% (75·1%, 89·1%)	89·1% (85·2%, 92·2%)	41·8% (34·2%, 49·7%)	62·7% (52·6%, 72·1%)	89.6% 88.6-90.6
	Current	84·5% (82·0%, 86·8%)	83·5% (80·2%, 86·4%)	70·6% (67·8%, 73·2%)	58·5% (49·3%, 67·3%)	80·5% (75·8%, 84·6%)	36·4% (29·0%, 44·2%)	51·0% (40·9%, 61·0%)	74.8% 73.3-76.3%

Note: Results were weighted for survey non-response bias· Chemotherapy omitted due to less than 5 respondents· Respondents may have more than one symptom·

RP: Radical prostatectomy, EBRT: External beam radiotherapy, HT: Hormone therapy, BT: Brachytherapy, MON: Monitoring

CI: Confidence interval

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Figure 1 - **Recruitment of prostate cancer survivors**

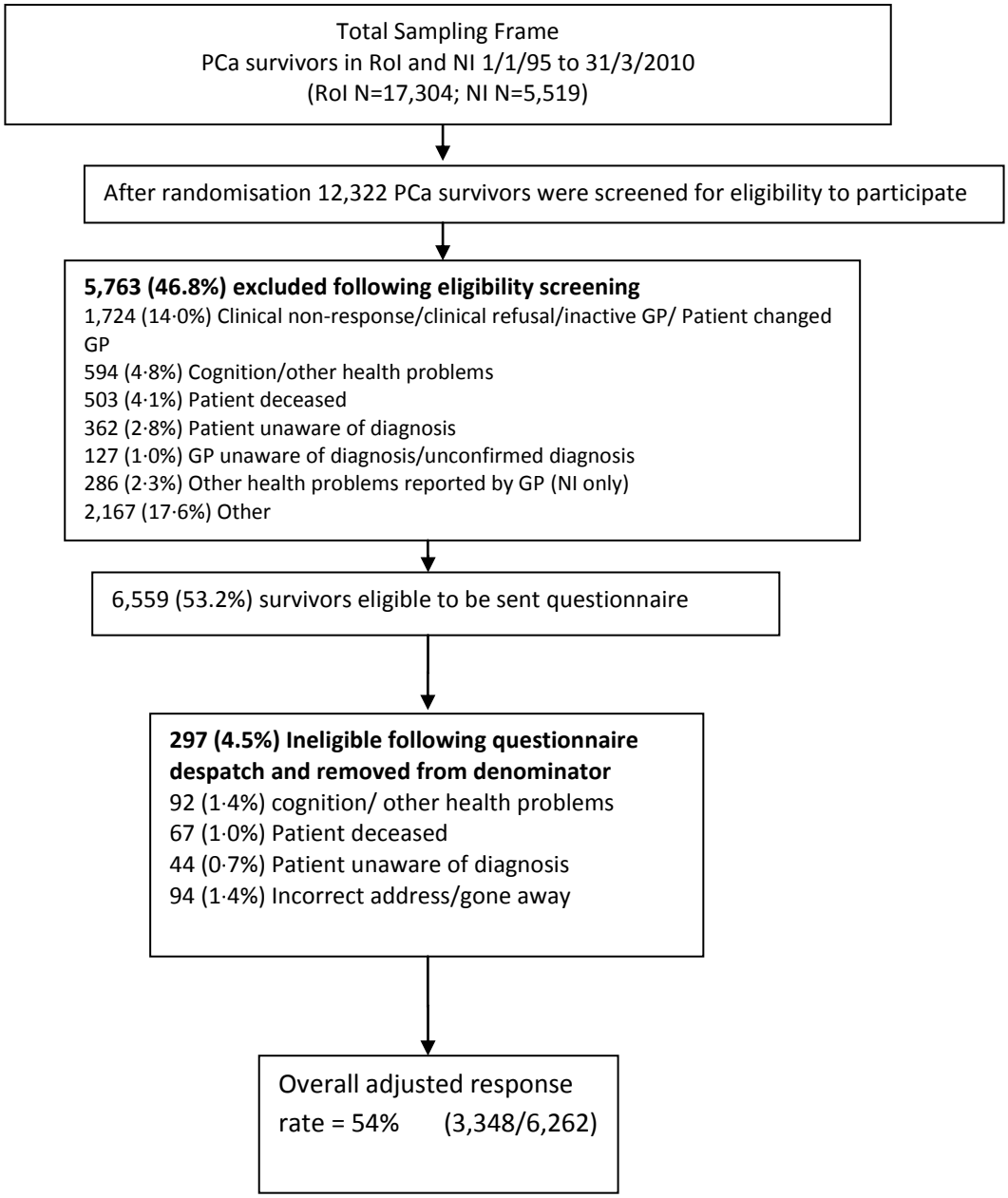

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Figure 2a: 'Current' impotence, incontinence and bowel problem **Figure 2b: 'Current' loss of libido, breast changes, fatigue and hot**

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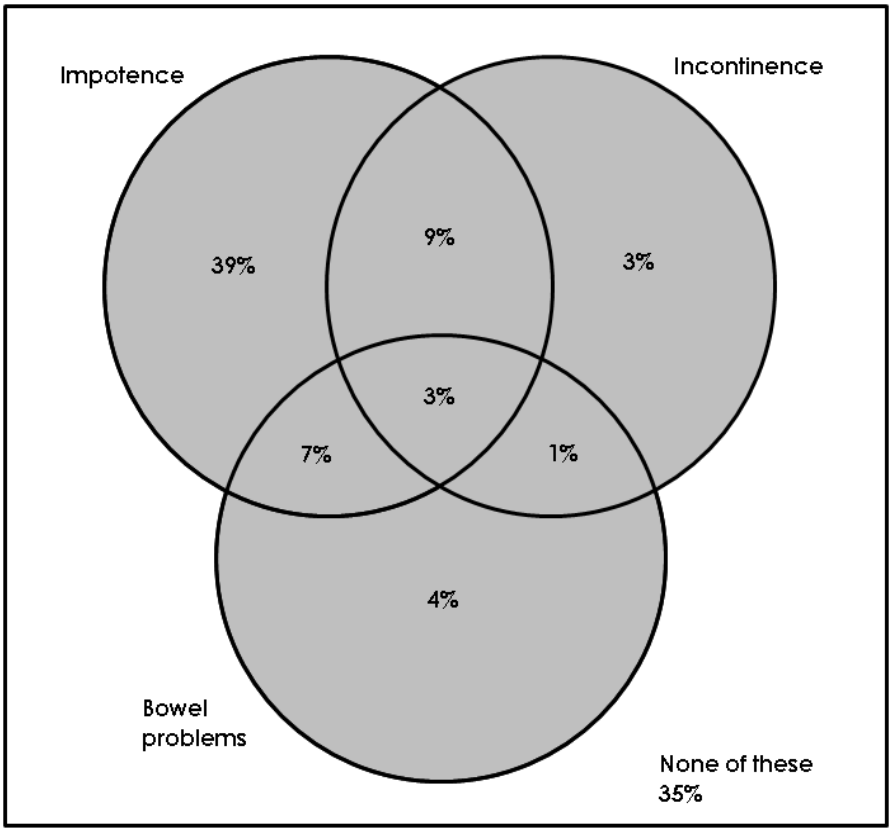
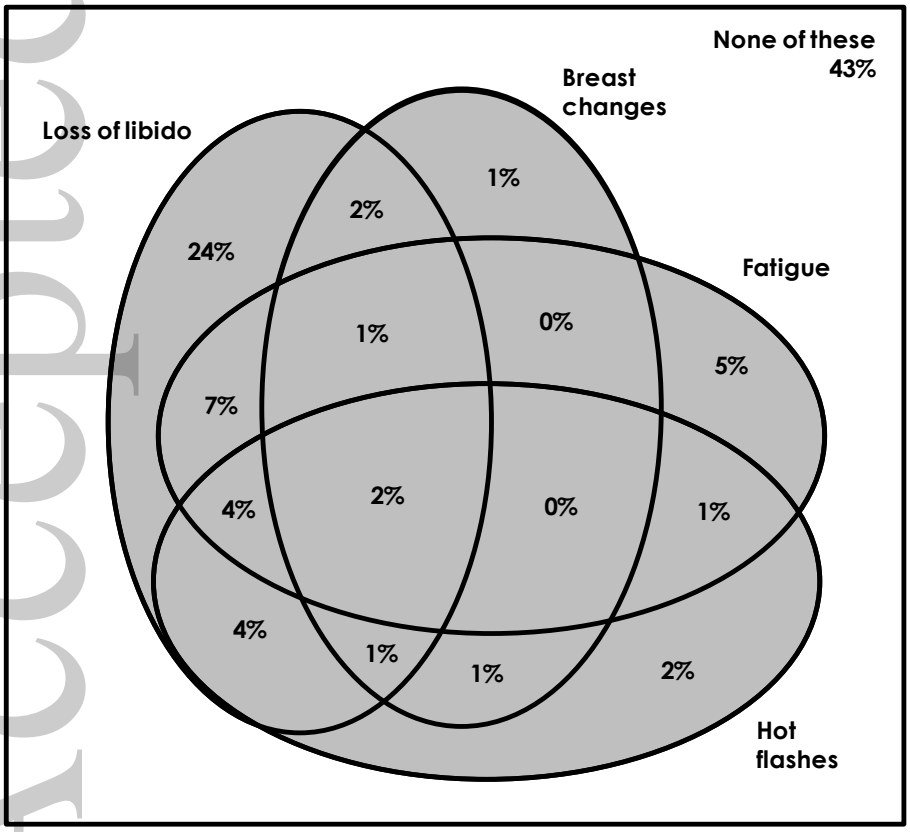


All respondents n=3,348

flashes



All respondents n=3,348

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Figure 3a - Impotence pre treatment and currently

Figure 3b - Loss of Libido pre treatment and currently

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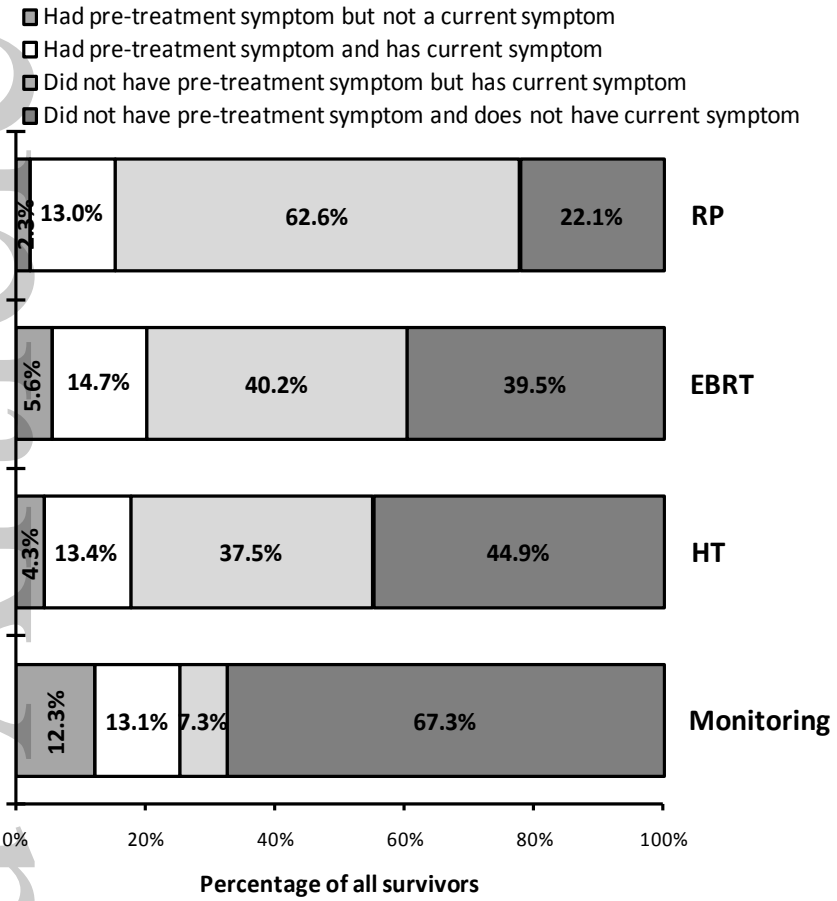

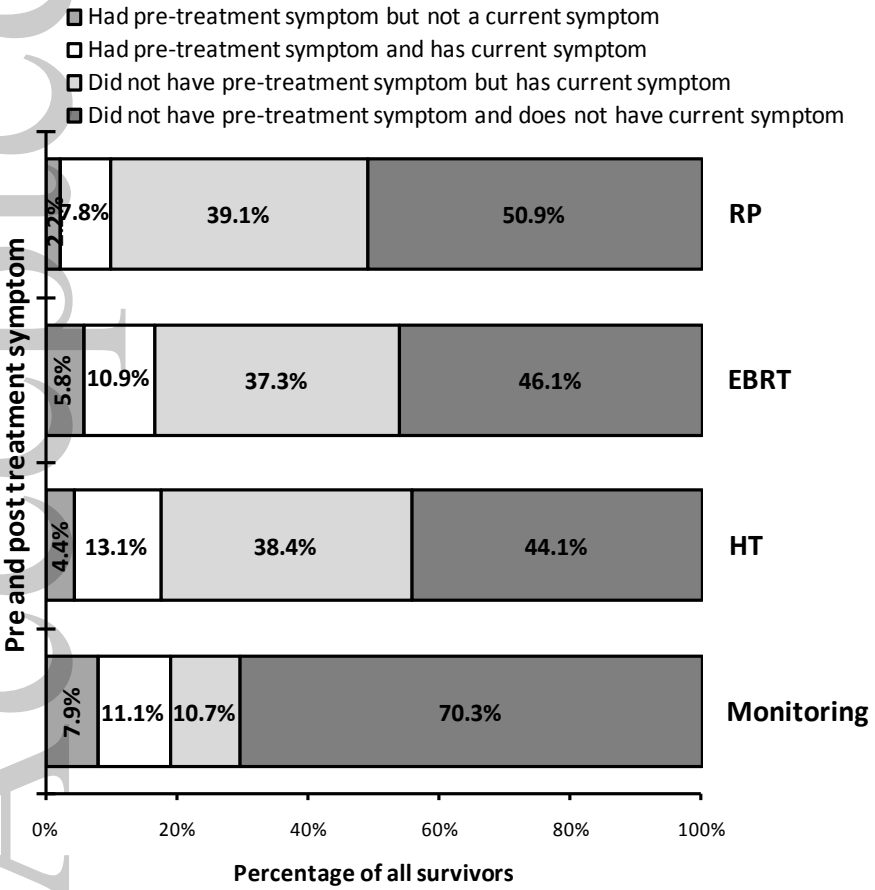

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All = all patients, RP = radical prostatectomy, EBRT = External Beam Radiotherapy, HT = Hormone Therapy

Note: Only impotence and loss of libido are compared pre- and post-treatment as definitions for other conditions differed pre and post treatment.

Accepted Article

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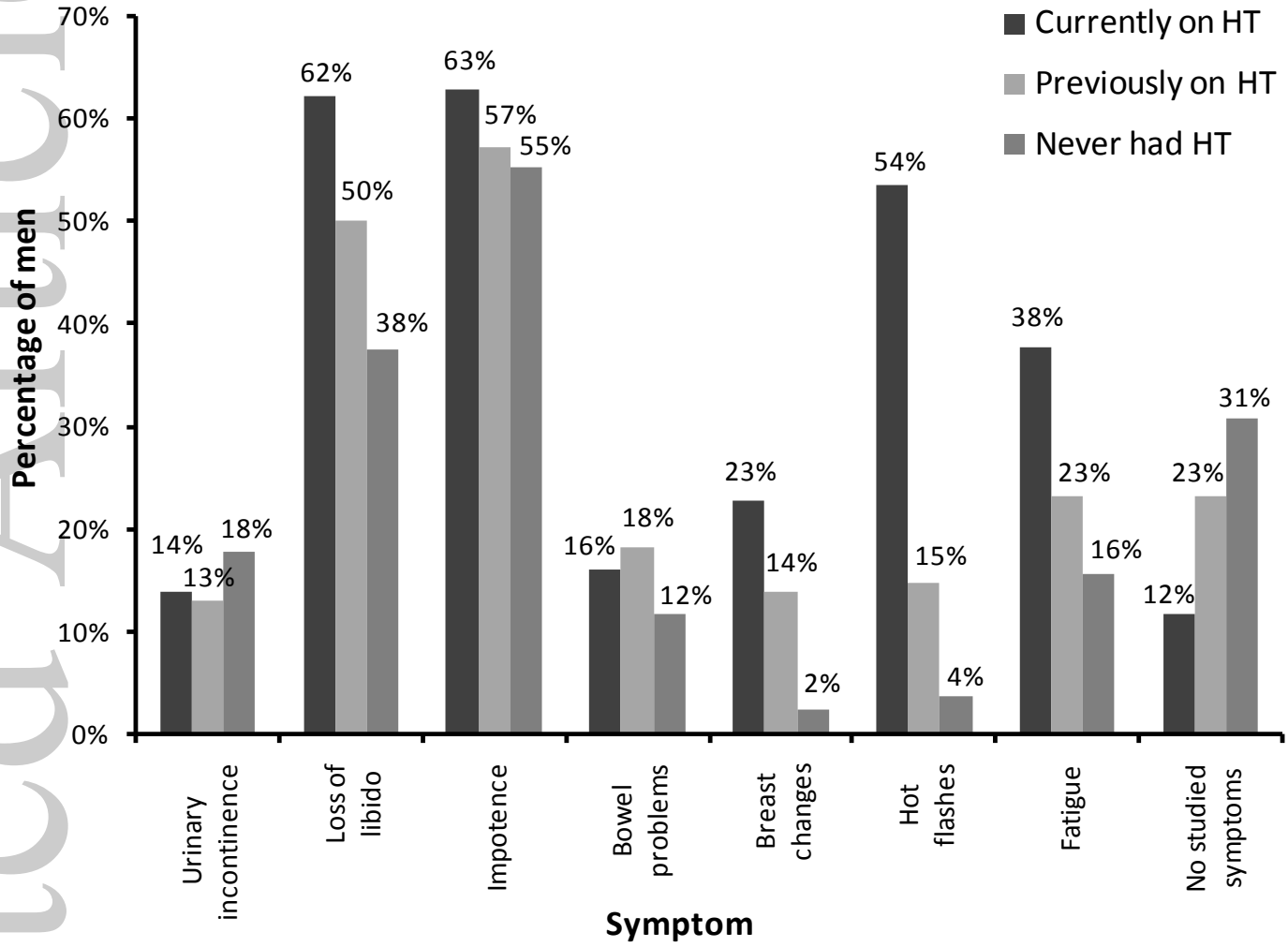
Figure 4 - Current symptoms reported by prostate cancer survivors by hormone therapy utilisation



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